

# The Leeds Haemophilia Comprehensive Care Centre

Information for patients



Welcome to the Leeds Haemophilia Comprehensive Care Centre Adult service based at St James's Hospital . If you have been diagnosed with an inherited bleeding disorder or are being investigated for a bleeding tendency, we would like to give you some information regarding your care, our contact details and the services we provide.

Our medical and nursing staff are experienced in the diagnosis and treatment of inherited bleeding disorders.

*Specifically we:*

- Provide 24 hours a day, seven days a week consultant emergency advice and care for those living with inherited bleeding disorders.
- Deal with all routine treatments required by people with haemophilia and other bleeding disorder including arranging home delivery of treatment for prophylaxis regimens for those who are in need of them.
- Facilitate emergency and elective procedures including dental, orthopaedic, endoscopy, gynaecology and obstetrics.
- Run specialist clinics including: Haematology obstetric clinic, Orthopaedic Multidisciplinary team virtual clinic and specialist combined physiotherapy and podiatry clinic.
- Signpost you to social work/benefit advice.
- Arrange and obtain blood tests when required for analysis in our specialist laboratory.

- Co-ordinate home delivery services and provides support for patients and their families.
- Offer community visits by the hospital based nurse specialist and/or the physiotherapy specialist.

## The outpatient facilities

The main Haemophilia clinic is generally run on Tuesday mornings and is located on Ward J87, Haematology Outpatients on Level 3, Bexley Wing. Your first point of contact is likely to be our clinic clerk, as you check in at the desk. You will be asked to take a seat in the waiting area where free tea and coffee facilities are available - so please help yourself.

Before seeing one of your specialist consultants, the haemophilia clinical support worker will take your weight/height and other routine observations such as your blood pressure, pulse and temperature.

You will then be called by the doctor who is seeing you and taken to the consulting room, where you will also have the opportunity to meet the nurses and physiotherapists. If you have moved from children's services (transitioned) you are likely to have already met one of the nurses and already know the physiotherapists, we hope this will make your first appointment easier.

If you have a bleeding disorder card, please bring this to clinic so we can make sure the information is still relevant.

If you need an interpreter for your appointment please mention this to the GP at the time of your referral and following your first appointment this will continue within our service.

## Inpatient facilities

If you are admitted to hospital with a problem associated with your bleeding disorder, you may first be assessed on Ward J95, Level 5 Bexley Wing, St James's Hospital, LS9 7TF, direct contact number **0113 206 8395**.

Depending on the outcome of your assessment you may be admitted to Ward J96, located on the same floor of Bexley Wing, direct number **0113 206 9196** this is a general admissions ward. If you require a longer stay you will be moved to one of the Haematology wards.

### *Please see below:*

The two Haematology wards in Bexley Wing are located on Level 3:

Ward J88 direct number **0113 206 9188** and

Ward J89 direct number **0113 206 9189**.

For teenagers and young adults (18 to 24 years of age) there is also Ward J94, located on Level 5 Bexley Wing, direct number **0113 206 9194**. This ward is also referred to as the Teenage Cancer Trust Young Adult Unit.

## Other admissions

Your GP may refer you to other specialties, if there is a chance this may require an invasive procedure or surgery, you should ask for a referral to the Leeds Teaching Hospitals.

If you require an admission for surgery or a procedure you will be admitted to the ward where the surgical team are based and will be under their direct care. The haemophilia team will work closely with the surgical team to provide advice and

support throughout your time in hospital and during your discharge planning.

## The Adult Team Members

*The Adult Team caring for you is made up of;*

- Haemophilia Clinical Lead
- Consultant Haematologist
- Clinical Nurse Specialists
- Haemophilia Physiotherapists
- Podiatrist
- Haemophilia Clinical Support Worker
- Psychologist
- Administrator
- Secretary

## Useful Contacts

If you need help or advice from the nurses please call us on **0113 206 8321**, there is an answerphone where you can leave a message if we are unavailable and we will call you back as soon as possible.

To arrange appointments or support from the physiotherapy team please call **0113 206 8373**, answerphone facility is also available on this number.

To access the medical social worker, please speak to your nursing and physiotherapy team. They can help support patients with issues such as benefits advice.

Access to the youth worker would also be via a team member.

For clinic appointments and administration queries please contact: **0113 206 8458**.

In an emergency or out of hours you must contact Ward J88 on **0113 206 9188** or Ward J89 on **0113 206 9189**. The nurses will then triage/direct your call.

In the event you are in the accident and emergency department, please show your **bleeding disorder card** to the team. You should highlight the information on the back of your card and prompt the team to contact the on-call doctor for haemophilia.

## **Feedback and Complaints**

Your feedback is important to us and in order to improve the service we deliver we welcome any comments you would like to make. Sometimes we may ask you to complete a questionnaire in clinic regarding our services.

We would also appreciate that if you visit the Haemophilia centre you complete a Friends and Family Test form that are available on the reception desk.

If you wish to make a complaint there are leaflets within reception that detail how to do so. The trust Patient Advice and Liaison Service (PALS) are available for all patients to ask questions, complain, give feedback or help with advocacy services.

**<https://www.leedsth.nhs.uk/patients-visitors/patient-and-visitor-information/patient-experience/patient-advice-and-liaison-service-pals-and-complaints/>**

## Useful Links

### World Federation of Haemophilia

International resource with information and guidelines on bleeding disorders. [www.wfh.org](http://www.wfh.org)

### Haemophilia Society

A UK based support group with useful information on bleeding disorders. [www.haemophilia.org.uk](http://www.haemophilia.org.uk)

### National Haemophilia Database

Once a diagnosis has been made your doctor/nurse will discuss registration on the National Haemophilia Database (NHD). This is a register of all UK patients with a variety of bleeding disorders. The database is managed by the UK Haemophilia Centre Doctors' Organisation (UKHCDO). This link takes you to leaflet that explains how the data and information we provide is used. [www.ukhcdo.org/nhd](http://www.ukhcdo.org/nhd)

### Haemtrack

This is a website where patients are actively encouraged to use to record their factor treatment when receiving prophylaxis. Healthcare professionals can then login to see this data and support patients in maximising their treatment.

<http://haemtrack.mdsas.com>

**However, if you are experiencing any problems please contact your nurses.**

### The European Haemophilia Network (Euhanet)

A locator of haemophilia centres in Europe for travel information. [www.euhanet.org.centrelocator](http://www.euhanet.org.centrelocator)



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Produced by: Medical Illustration Services • MID code: 20230913\_004/JG

LN004642  
Publication date  
09/2023  
Review date  
09/2026